Experience of stigma in private life of relatives of people diagnosed with schizophrenia in the Republic of Belarus

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Abstract

Purpose

Family stigma constitutes a major problem in schizophrenia worldwide. Data on first-hand experience of stigma in families is necessary for planning and implementing interventions to reduce its burden. The aim of the study was to investigate the experience of stigma among relatives of persons with schizophrenia in Belarus.

AQ1

Methods

Qualitative research methods, such as the thematic analysis of in-depth semi-structured interviews with 20 relatives of people diagnosed with schizophrenia, were used. Experience of discrimination, strategies used to cope with it, and requests for interventions were investigated.

AQ2

Results

The most salient themes in experience of stigma in the private domain of life elicited in the narratives included anticipated stigma and dissolution of families. The experience of stigma was associated with burdensome feelings of guilt, tiredness and loneliness, together with fear and anxiety due to uncertainty in the future and sorrow because of frustrated hopes in past. Analysis of the strategies used to overcome the difficulties revealed concealment and “life behind closed doors”, avoidance of the rest of the family, taking full responsibility and sacrificing one’s personal life.

Conclusion

To reduce the burden of stigma in the private life of the family members of people living with schizophrenia in Belarus, important steps should be taken to promote the empowerment of families including: reforming mental health services; provision of better access to information; family

support services, community care; development of family organisations; assistance in communication, re-socialisation and independent living for people diagnosed with schizophrenia.

Keywords

Family studies
Courtesy stigma
Qualitative approach

Introduction

Stigma of mental illness constitutes a major problem worldwide [1]. It not only affects people living with a mental illness [2], but also their families [3]. Referred to as “courtesy stigma” [4], “associative stigma” [5], “stigma by association” [6] or “family stigma” [7], it is widespread, and occurs across cultures, regardless of nationality and socio-economic status [8–12]. It exists in different domains of life [12] and is associated with both subjective and objective burden of family members (FMs) [6, 7, 9, 13–15].

A variety of campaigns have been undertaken to tackle stigma [1], and some have been shown to be successful [16, 17]; however, they are generally broad, non-specific, and their effect size is moderate [18, 19]. Interventions seeking to reduce stigma in the family context are scarce and rarely take into account the views of service users [18]. Further research is needed to better understand how stigma is experienced in the family context, and how these experiences vary in different cultural contexts, i.e. “what matters most” in different settings [20]. Information of this type is essential to inform the development of interventions that take into consideration the effects of stigma and its cross-cultural variability [18]. There is very little evidence available from Eastern Europe [21] and to the best of our knowledge, this is the first paper presenting first-hand experience of families of people receiving mental health care in Belarus. Information of this type is particularly important in countries of Eastern Europe as there is insufficient development of community-based treatment [22, 23] and most of the care for mentally ill people, particularly those who are severely and chronically ill depends on the FMs.

We undertook a qualitative study of the first-hand experience of FMs with three main objectives: (1) to investigate experiences of stigma-related challenges of the FMs of people living with schizophrenia (PLS) in Belarus, both in the private and public domain of life; (2) to identify strategies that FMs use to face the stigma-related challenges in Belarus; (3) to identify relevant and acceptable targets for interventions to help overcome stigma-related challenges for families within the Belarusian context.

There is a lack of widely accepted theories on stigma within the family. With an awareness of the existing conceptualizations of stigma [20, 24–28], we upheld a broad perspective and took an inductive approach to the experience of stigma rather than the process of stigma per se. Therefore, the analysis was focused on "the direct experience of stigma-related challenges by FMs of PLS", and specifically any examples of devaluation experienced by FMs either in the private or public domain because of the presence of schizophrenia in the family. By "private domain of life", we meant personal relationships, interests, and activities as distinct from public or professional life [29] and focused on discrimination within a family, in relationships with neighbors, friends and colleagues. In contrast, by "public domain of life" we meant experience of contacting social institutions and focused on stigma and discrimination in these contexts (within health care system, while contacting police, during employment and education).

We here present results related to the experience of stigma and discrimination in the private domain of life of FMs of PLS. The materials of the study related to the stigma and discrimination in the public domain are available on request from the authors and will be published in a separate paper.

Methods

The research participants were recruited via purposive sampling in both Minsk and Grodno, so as to obtain data from the capital and a regional city. To achieve maximum variation, we recruited cases according to the following core attributes for the sample: FM and PLS sex and age (less than 30, 30–50, more than 50 years), duration of disease (less than 1, 1–5, 5–10, 10–20, more than 20 years), degree of kindred (first degree relative

(mother, father, sibling, adult child, partner), second degree relative, distant relative or other).

Before approaching FMs, we contacted the patients, described the study and asked them for permission to approach the nominated FM. After obtaining the permission, researchers (DK, NK) contacted the selected FMs, described the study, asked them to sign informed consent and conducted semi-structured in-depth interviews [30]. A topic guide was developed based on a literature review [4, 10, 15], consultations with service users and mental health professionals, which was piloted during initial interviews (it is given in Appendix 1). Interviews lasted approximately 1.5 h, were conducted in Russian, recorded digitally, and transcribed verbatim.

Two bi-lingual members of the research group (DK, NK) proceeded with the thematic analysis [31] in Russian. Coding of the interviews was done by hand and both analysts independently processed each interview. Analysts initially familiarized themselves with the data by listening to the recordings and transcribing them. Words, phrases and larger sections of text were highlighted and coded to identify relevant themes. Discrepancies in the coding were discussed and resolved. The final list of themes was discussed with other members of the research team and adjusted until final agreement was reached (the list of themes related to both private and public domain of life is presented in Appendix 2). The final results and supporting quotations were translated into English and double-checked by bi-lingual (DK, NK, NB) and native English-speaking (SD, JM) authors.

The study was approved by the Ethical Committee of Belarusian Psychiatric Association (approval no. 1/e from 27 February 2014).

Results

Participants

The final sample consisted of 20 relatives, which included mothers (40 %), fathers (20 %), spouses (10 %), children (10 %) and distant relatives (20 %) such as cousins and nephews. The main socio-demographic characteristics of the sample are shown in Table 1. Median age was 52 years (IQR 40, 62), 45 % of participants were males, and 45 % married at the time of the interviews. Half of PLS were in tertiary care at the time

of the interview with FMs.

Table 1

Socio-demographic characteristics of the sample

Variable	***N* (%)**
Information about respondents	
Gender of respondents	
Male	9 (45)
Female	11 (55)
Age of respondents [median of age (IQR)]	52 (40, 62)
Marital status of respondents	
Single	6 (30)
Married	9 (45)
Divorced	5 (25)
Place of residence of respondents	
Minsk	10 (50)
Grodno	10 (50)
Family relationship to a patient	
Mother	8 (40)
Father	4 (20)
Spouse	2 (10)
Children	2 (10)
Other (siblings, distant relatives)	4 (20)
Family members who are primary caregivers	13 (65)
Family members living together with patients	14 (70)
Information about patients	
Gender of patients	
Male	5 (25)
Female	15 (75)
Age of patients [median of age (IQR)]	35 (28.5, 38.7)

Marital status of patients	
Single	3 (15)
Married	7 (35)
Divorced	10 (50)
Length of patients disorder (years)	
Less than 1	1 (5)
1–5	2 (10)
5–10	5 (25)
10–20	9 (45)
More than 20	3 (15)
Service utilization at the moment of interview	
In-patient treatment	10 (50)
Out-patient treatment	10 (50)
IQR interquartile range	

Stigma experience

Following thematic analysis of the interviews, we grouped the experiences of FMs into three main themes: (1) challenges in the private domain; (2) subjective burden and feelings associated with experiences of stigma; (3) challenges in the public domain. As previously mentioned, results related to stigma in the public domain are covered in a separate paper, and are available from the authors.

Challenges in the private domain

Experience of stigmatization in the private domain is covered within two subtopics: (1) attitudes within close environment and (2) life within the family.

In relation to the attitudes within close environment (within secondary social group: with friends, neighbors, colleagues) nearly half (45 %) of respondents expressed suspicions (beliefs without necessary confirmation) that derogatory attitudes are hidden (“behind my back”) and/or apprehensions that there may be “bad” or “dangerous” consequences to the

whole family if revealing the diagnosis. The most obvious consequences that FMs anticipated were condemnation of the whole family, difficulties for other children to find a spouse, job, or build a career. However, the suspicions and/or apprehension were not always backed by reported experience. The majority (7 out of 9) of those expressing the suspicions and/or apprehensions could not remember any examples of directly stigmatizing attitudes and were in general satisfied about the relationships with friends, neighbors and colleagues.

> "It is a bad mark for the whole family." (Mother, ID20).
>
> "There were no cases someone would have told me directly. However, some visitors looked so… well… you feel it in their glance that they do not like something. Something for them is… well, you see their attitude. It is like when there is a limping person who is walking. Something like this but hidden deep, deep inside." (Husband, ID11).
>
> "So, I do not tell anyone. There is a mentality here that if someone is under psychiatric registration or, heaven forbid, is admitted to "Novinky" (name of the most famous psychiatric clinic)—that's the end! It is a family! You know, I have a younger daughter, do you understand? It is very difficult, we are afraid of it. It is a stigma of the whole family. I am a mother and I have a younger daughter who has good prospects, who is a respected person. Do you understand? This is an issue… I am even afraid to think what may happen. No, no, no. I will emphasize again—I am only afraid for my other daughter who is a very young, 21 years old. Her whole life is before her, she is going to start university, she is a nurse, and she needs communication. I do not want this to worsen." (Mother, ID5).
>
> "If someone from foreigners would know they would say "For what a reason do you live with this goose?". I am sure 1000 % I would hear it." (Husband, ID16).

In relation to the life within the family (within primary social group:

relatives, partners), half of the respondents described difficulties, with a tendency of families to come apart ("broken family") following the diagnosis of mental disorder. The breaking up of the family happened in different ways: (1) divorces from the PLS, with the PLS returning to the parental family (five cases); (2) former spouses initiating the process of governmental removal of children from the PLS' parental custody (two cases); (3) general reduction of contacts from the rest of the family with primary carer and a PLS (presented by 5 of 13 primary carers). As a consequence of such family break up, more than a third (40 %) of the FMs providing primary caregiving were the only people remaining in the life of PLS, and were bound to them without the possibility of temporal separation.

> "Her husband returned her to me and said: come and take back this schizophrenic." (Mother, ID3).
>
> "Children were taken away from her." (Father, ID8).
>
> "Everyone has abandoned him." (Mother, ID15).
>
> "X. once went to my brother, but they refused even to let him come into the house. X was sitting on the bench all the time. He (brother) called me and said: "Come here and take him back!" and didn't even allow him to enter, do you understand? …. Earlier we communicated somehow. But later when he married his wife forbade it because "Children will be afraid of X". That is it. Do you know how painful it is for me to bear this." (Mother, ID15).
>
> "My sister asks: "Why don't you visit me?" This summer I replied: "Ok, let me come with X!" She: "No, I do not need this tagalong". I.e. no one needs him. So, he will stay, and I even do not have anyone to be his guardian (crying)… So, everyone has abandoned him." (Mother, ID19).

Subjective burden

Respondents expressed a number of negative feelings associated with being part of a family with a PLS. Shame and/or guilt were the feelings

most frequently mentioned (by 50 % of participants) as burdensome in one form or another: (1) guilt for the lack of awareness of the need for treatment, denial of the need for treatment during the first years of the disorder; (2) “sins”, “bad actions” that were perceived as a possible explanation of the onset of the disorder (e.g. abortions, lack of love); (3) vague reasoning (“I know that it is my guilt, but I don’t understand what for”, “I just feel that I have made some mistake”); (4) shame caused by the patient’s bizarre behavior in public (intensive smoking, strange sounds, phrases).

FMs expressed fear, anxiety and hopelessness related to the presence of diagnosis within a family, which were mainly (for 50 % of respondents) connected to uncertainty about the future. Lack of support from the rest of the family and within the health care system worsened the situation. More than third of primary carers (5 out of 13) expressed tiredness, loneliness and regret as a consequences of the family dissolution following the diagnosis of schizophrenia.

> “What will happen after I am not able to care for X?” (Mother, ID3).
>
> “Who will take care of me when I am old?” (Mother, ID2).
>
> “I don’t see how it may be resolved” (Father, ID10).

Amongst other emotions, regret, sorrow and mourning, feelings of loss, frustrated hopes (“We were expecting her to be successful, but everything is broken now”) were often mentioned (45 %), as well as overload and depression (25 %) (“my life is broken”, “I am tired”, etc.).

In most cases (76 %), the first episode of psychosis, the first hospitalization and especially the first exposure to the diagnosis of “schizophrenia” were mentioned as the most stressful and difficult period for the whole family. Respondents remembered feelings of despair, hopelessness, shame, and fear.

> “I nearly died”, “It was a shock for me, and very strong. I cried for many years. I howled at nights… when you work, it’s possible to avert your attention… But when I went

> home, I howled at nights for many years." (Mother, ID15).
>
> "I was very upset, we were crying for weeks—me and my wife. We didn't know what to do. We felt bad… it was very hard in the beginning… there were thoughts that a person's life is crippled." (Father, ID10).

Strategies that FMs use to overcome stigma in the private domain

Strategies adopted by respondents to cope with stigma and discrimination in the private domain included: (1) concealment, (2) avoidance of the rest of the family and (3) taking full responsibility and sacrificing one's personal life. The whole set of strategies to cope with stigma and discrimination in both the private and public domain of life is presented in the Appendix 2.

Concealment ("live behind closed doors")

Suspicions and fear of experiencing derogatory attitudes towards the family, or lived experience of it, due to the presence of a PLS within the family, lead to the tendency to "live behind closed doors", hide, and to pretend a "normality in the eyes of others". More than a half (55 %) of respondents reduced contacts with the external world, and tried to avoid social activities. If these were unavoidable, they would prepare the PLS so that they looked and behaved "as normal" (e.g. smoke less, speak intelligently, wear clean and beautiful clothes). Even if the current situation resulted in a significant burden, the relative were not ready to implement any alleviating actions or share their difficulties with others.

Avoidance of the rest of the family

More than two-third (5 out of 7) of FMs who were not primary caregivers expressed a tendency to stay away from PLSs or even leave the family because of "lack of practical knowledge", general "tiredness" and "fear of consequences" for their personal life and career if the diagnosis within their family was disclosed. At the same time, they mentioned feelings of shame and guilt because of this.

Taking full responsibility and sacrificing one's personal life

Insufficient support in mental health care and from the rest of the family, and living life “behind closed doors” whilst avoiding contact with the external world led to FMs bearing substantial responsibility for the actions of PLS, and totally controlling their decision-making. The majority of primary caregivers (77 %) mentioned this. At the same time, FMs were usually aware of the necessity to reduce control over the PLS’s actions, so as to increase their autonomy.

> “We all must somehow to let children go. However, he is “like this” (meaning mental illness). But even if he is “like this”, he also must be somehow, slightly, although maybe not totally, released (from parental family)… but I don’t know how.” (Mother, ID1).

Respondents expressed perplexity in such ambivalence and lack of knowledge on how to manage the situation. The intense devotion to the life of the PLS led to FMs sacrificing their own personal lives, (“My life is totally her/his”) with an inability in some cases to even express their own needs (“My only dream is to return my daughter to a normal state, I have no other dreams”).

Requests for interventions to decrease burden of stigma and discrimination in private life of FMs

Interventions mentioned by respondents as possibly helpful to decrease stigma-related challenges in the private domain included (1) provision of better access to appropriate information and (2) assistance in the life of PLS.

Information and education

One of the main needs of FMs mentioned by 40 % of respondents, was that of access to correct information that is delivered sensitively. Part of the request was related to advice on ways of treating and managing relapses, and of solving difficulties in relationship within a family, e.g. how to communicate with other FMs and PLS, how to discuss challenging situations within the family. Although there are taboo or difficult issues that need to be discussed, but relatives either do not know how to raise these issues, or are afraid of doing so (e.g. “how to discuss with patient

his/her concerns on sexuality?", "How to talk to the rest of the family which has separated from the patient?").

> "What I would like to change in the medical services is to increase the quantity of available information… about new approaches. And it should not be my responsibility to elicit this information, but someone else who will give it to me… but there is nobody…" (Father, ID10).
>
> "I would like to be guided when I address the doctor. How should I behave in these situations? Should I call the police or should I not? Should I wait for X. or talk to her somehow specifically? How to behave, how to act? How to persuade her? I.e. I need some kind of recommendations on how to behave with her." (Mother, ID13).

Assistance in the life of PLS

Nearly half of respondents (45 %) also expressed a wish to help the patient with having more communication with peers, assist them in socializing and in living a more independent life.

> "I would be happy if there were at least somewhere where he could spend time with peers drawing or doing some job", "I only want him to be able to communicate more with his peers." (Mother, ID12).

Discussion

The results of the study shows the presence of stigma experience in the private life domain of the family members of people living with schizophrenia with a specificity of the stigma experience in primary and secondary social groups. Life within primary social group (in relationships within family) was described as changed after onset of mental disorder mainly because of dissolution of families ("broken family"). On the other hand, within secondary social group (in relationship with friends, neighbours, colleagues) stigma was perceived as problematic predominantly due to suspicions of hidden discrimination ("behind the back") and apprehension of bad consequences in the case of the diagnosis

disclosure, although there were relatively few examples of perceived stigma, and direct discrimination.

Whereas experience of perceived stigma within a primary social group was salient in the study, this was not the case in the secondary social group. There was a contradiction between anticipated and perceived stigma while contacting outsiders. On the one hand, respondents presented feelings of fear, suspicions and apprehension of possible hidden discrimination and its consequences. On the other hand, the majority of these respondents could hardly remember real examples of discrimination and were satisfied with the relationships with friends, neighbours, colleagues. This contradiction was previously discussed in relation to associative stigma by Catthoor et al., who noticed a marked difference between the presentation of the perceived stigma and feelings associated with it. In particular, respondents claimed there were no problems in contacting outsiders although they tended to conceal and keep the disorder secret [11]. This phenomenon of mismatch between experienced and anticipated discrimination was described even more thoroughly in research on stigma towards people with mental disorders. It has been found that anticipated discrimination was reported more frequently then experienced acts of discrimination and not necessarily associated with it [2, 32].

The described mismatch was however not found within the primary social group in the current study, where clear examples of family dissolution with consecutive challenges and subjective burden of caregivers were presented. This is in line with other research showing relationships problems within the family [33, 34] and deterioration of relationships with extended family because of a relative with a mental illness [6, 9, 13, 14].

According to the theory of Yang et al. [20] the culture influences stigma by determining “what is most at stake for actors in a local social world” and what is threatened most of all by stigma in the particular culture. From this perspective, the results of our study suggest that the family image is the main value under threat of stigma in private life of relatives of people living with sczhizophrenia in Belarus. Respondents expressed a fear of the consequences of diagnosis disclosure mainly because of the possibility that the whole family would be condemned and both patients and other relatives not affected by disorder may have difficulties in creating own family and building a career. The importance of family is not surprising as

it is typical for Belarusian culture what was shown by the World Values Survey [35], where family was ranged as the most important value (98 % ranked it as very or rather important).

The literature on coping strategies for carers of people with psychosis [36–40] has highlighted the importance of understanding both the severity and scope of the problems, and how carers appraise the situation and cope with it [37, 38, 41]. Adequate coping strategies promote good living environments and reduce the level of expressed emotion, which have been shown to play a substantial role in both the burden of carers and patients outcomes [42–44]. Life behind closed doors, avoidance of distant relatives, taking full responsibility for the life of patients and sacrificing one's personal life were the strategies mentioned by the study's respondents in relation to stigma in the private domain. The overall solution to cope with stigma-related challenges in the family was "living a hidden life" or "behind closed doors". This strategy resulted in social exclusion of the direct caregiver, and burdensome feelings that included guilt, tiredness and loneliness, together with fear and anxiety due to uncertainty in the future and feelings of loss and frustration because of hopes for a better life held in past.

In summary, according to the data of the current study, stigma experience in the private life of family members of people living with schizophrenia includes (1) anticipated stigma within the secondary social group; (2) dissolution and lack of support within families; (3) strategies to conceal disorder, living a hidden life behind closed doors and taking full responsibility for the life of the patient; (4) being exposed to resulting subjective burden.

In a situation of this sort, access to appropriate support and assistance provided by mental health care could improve the quality of life of family members. However, mental health care in Belarus is hardly able to provide such support, as it has just recently started a deinstitutionalisation process of its services [23, 45] and is still based in centralised psychiatric hospitals (which have up to 1700 beds in Belarus). Institutionalised mental health services are known as associated with structural stigma, bad living conditions [46, 47], human rights abuses and negative outcomes from long-term treatment [48]. Lack of appropriate support from mental health service, absence of peer support groups, patients and family organizations

in Belarus make the situation even worse. Breaking the vicious circle of disempowered families and non-responsive mental health service is an important direction for addressing the burden of stigma within families of people with schizophrenia in Belarus, what should be a priority for reforms of mental health care.

Number of approaches have been offered to tackle stigma and discrimination [49, 50]. We recommend the implementation of several such strategies in Belarus. For example important steps to be taken include: empowerment of family members as well as people with schizophrenia themselves; their inclusion in decision- and policy making; reforming mental health service with increased access to care within communities; development of family support services; facilitating appearance of service users and family organisations; assistance in communication, re-socialisation and independent living of people diagnosed with schizophrenia [49].

Strengths and limitations

There are a number of limitations to our study. Firstly, it is difficult to generalize the results because participants were recruited through mental health services, potentially resulting in the over-representation of the views of people who are in touch with services. Secondly, interviews were conducted and analyzed by researchers (DK, NK) who are both clinical psychiatrists from Belarus. This may have led participants to focus more on their experiences from the perspective of mental health services. Third, difficulties with conceptualisation of the phenomenon studied must be taken into account. It was at times not clear where to draw a line when trying to separate direct experience of discrimination from indirect. The difficulty in separating direct and indirect experience of discrimination was also an issue in other studies on courtesy stigma [4, 15], where “it appears to be difficult for relatives to draw the line between negative reactions targeted at themselves and those targeted at mentally ill. Relatives feel, thus, stigmatized in a double sense” [4]. In addition, stigma is a complex phenomenon multiply interwoven with other life experiences such as burden, illness manifestation, relationship within a family, social interactions, contacts with health service and other public institution [6, 51]. Therefore, it was not always possible to differentiate whether the topic discussed was related to stigma, to its consequences or to some other

concept (e.g. burden). However, the study has many strengths, including: the use of an inductive approach in the analysis of participants' accounts of their experiences; involvement of mental health professionals and service users while planning and conducting the study.

Practical implications

Based on the results of the study a set of recommendations on reduction of stigma-related burden in Belarus might be produced. To tackle the stigma and discrimination in families of people living with schizophrenia it is important to promote empowerment of families, their inclusion into the decision- and policy-making processes. Other important components would include providing better access to correct information, support of people living with schizophrenia in their communication skills, re-socialisation and independent living.

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Compliance with ethical standards

Conflict of interest Authors have no interests to declare.

Appendix 1

Topic guide for interviewers

- Social and personal life (friends, neighbours, leisure, holiday, shopping, religious and cultural life);
- Life within a family (attitude with people living with schizophrenia, relationship with other family members, changes in family after diagnosis, support and conflicts inside of family);

- Feelings associated with being relative of people living with schizophrenia;
- First experience of hearing diagnosis;
- Education and employment (barriers, deteriorations);
- Finance (problems, income influence, access to loans, welfare payment);
- Experience of contacting both mental and physical health care system (treatment, hospitalization, contact with psychiatrists and other doctors);
- Accommodation issues (deterioration, general conditions, access to basic needs);
- Legal issues, contacts with police (attitude of police, experience of detention, access to mental health care);
- Ways to cope with raised challenges;
- Requests of interventions to reduce burden and improve the situation.

Appendix 2

List of identified topics of stigmatization experience, coping and intervention requests of family members of people living with schizophrenia

Experience of stigma and discrimination of relatives of people diagnosed with schizophrenia
Challenges in the private domain
Attitude within close environment (suspicions and apprehension of stigma)
Life within a family (“broken family”)
Subjective burden
Feelings of guilt, sinfulness, fear and anxiety, hopelessness, sorrow, shame, overload and depression
Stressful first episode of disorder

Challenges in the public domain
Associated with mental health care
Difficulties in contacting mental health professionals and their attitude towards PLS
Lack of alternatives to hospital treatment
During hospital treatment of PLS (long travelling distances, lack of time and space when visiting, difficulties in contacts with medical staff)
Absence of alternatives to long-term residential care facilities
Difficulties getting appropriate information (poor contact with medical specialists; inconsistency of information; lack of information during the initial stage of disorder)
Associated with employment of PLS
Associated with contacting police
Strategies that FMs use to cope with stigma
In the private domain
Concealment (“live behind closed doors”, “normality in the eyes of others”)
Avoidance of the rest of the family
Taking full responsibility and sacrificing one’s personal life
In the public domain
Humility and passive acceptance
Self-reliance
Emotional containment during crises
Intervention requests
In the private domain
Information and education
Assistance in patient’s life (communication with peers)
In the public domain
Passivity in expression and scepticism in expectations
Changes in mental health care service
Alternatives to hospital treatment of PLS
Alternatives to psychopharmacological interventions

Alternatives to long-term care facilities and independent living of PLS
Assistance in patient's life
Communication with peers
Better legal defence
Assistance in employment

PLS people living with schizophrenia, *FMs* family members

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